



February 2002

## NAVIGATING THE SYSTEM

### User Guidebook Being Developed

*Submitted by Andrea Childs, Manager of the Office of Consumer and Family Support*

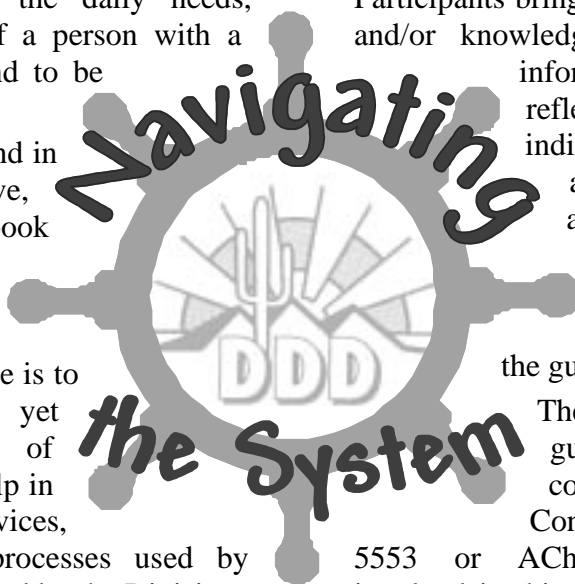
Many people have voiced frustration dealing with complex systems and red tape when trying to meet the needs of people with developmental disabilities. Individuals and families have expressed the need for timely, accurate and comprehensive information to assist them in managing the daily needs, challenges and activities of a person with a developmental disability and to be better advocates.

The Division, in response and in continuing efforts to improve, is developing a guidebook using input from families, consumers, advocates, community partners and Division staff. The objective is to publish a comprehensive yet easy to use guidebook of necessary information to help in navigating the systems, services, supports, resources and processes used by consumers and families served by the Division.

Between January and June of 2002, eleven separate groups comprised of individuals with developmental disabilities, family members, advocates, service

providers and state staff will be asked for their input and ideas about the kind of information the guidebook should include. Each group will review existing information, determine where gaps might exist and draft information to fill these gaps. Participants bring their special expertise, experience and/or knowledge ensuring that the guidebook information will be comprehensive and reflect the areas that families and individuals most often have questions about. Those participants who are also individuals with developmental disabilities or family members will be key in this process since they are the primary audience for the guidebook.

The Division's plans to have the guidebook "Navigating the System" completed in the fall of 2002. Contact Andrea Childs at 866-229-5553 or [ACHilds@mail.de.state.az.us](mailto:ACHilds@mail.de.state.az.us), to get involved in this process by either attending one of the many meetings or by reviewing drafts of the completed sections.



# MESA POLICE EXCHANGE EDUCATION

*Submitted by Sheila Maguire Al-Musallam, Investigator District I*

The Division and the Mesa Police Department are exchanging training and informational sessions. The need came after a recent encounter between Mesa Police and a resident of a group home that resulted in the death of an individual. The outcome might have been different or at least less severe, if each side had better understood the other.

Mesa Police Sergeant Michael Thompson trained District I Division management on January 22 and February 27. The next training is scheduled for May 15. Sergeant Thompson addresses how police view a call to an emergency scene and how they are trained to respond. In exchange, Sheila Maguire Al-Musallam, Division Investigator District I, will hold her first class in March for the Mesa Police. She will provide information about individuals with developmental disabilities and how to access relevant resources, such

as behavioral health professionals. The Mesa Police Department has made this mandatory training. Sheila also provides the Mesa Police with locations of group homes and any information about an individual that might be important for them to know prior to arriving on the scene, such as what might trigger an aggressive behavior or if an individual is non-verbal.

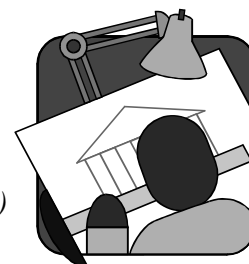
This cooperative exchange is a positive step that the Division hopes to expand to include caregivers and interested parties statewide. Contact Sheila Maguire Al-Musallam at 480-831-1009 for more information.



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## HOME MODIFICATIONS Thanks from Cindy Cunningham

*The following is reprinted with permission of Cindy Cunningham. It is part of a letter written to Jim Anderson, Home Modifications. Contact Jim at 602-542-6794 for more information about the Arizona Health Care Cost Containment System (AHCCCS) program for home modifications.*



1-17-2002

Dear Jim,

My name is Cindy Cunningham. My daughter's name is Lia De Orio.

Thanks to you, and a few other people who all worked hard to bring my new environmental modification into the light, my life is already ---- BETTER!!

Eric Juergens and his talented team entered my home on January 2, 2002. It really wasn't difficult having the men working here. We all got along, and were considerate of each person's job. Everyone was important and had a purpose. It went smoothly!!...

Having the work completed in my home is more that I ever dreamed. The ramp out front helps so much when wheeling Lia in the house. The tile, of course, is cleaner and also easier to wheel Lia around the house. The new bathroom is already better for my back, when I bathe her, and safer for Lia.

No one can tell me how long my special blessing of a daughter will be here to learn and to live, but taking care of her is great.

So thank you Jim...

Cindy Cunningham

# FAMILY/GUARDIAN SURVEY

State of Arizona is one of twenty-one states that participates annually in a random consumer survey sent to parents or guardians of individuals with developmental disabilities. The National Association of State Directors of Developmental Disabilities Services (NASDDDS) sponsors the survey. The latest survey results are from those states that have an individual living in a residential placement. In Arizona 80% of the families or guardians surveyed represent people living in group home settings. The survey questions are listed below with the percentage of responses of “yes, or mostly”. The satisfaction level of those surveyed in Arizona overall are well above the overall average.

	ARIZONA	AVERAGE OF THE PARTICIPATING STATES
<b>Information and Planning</b>		
Did you get enough information to participate in planning services for your family member with a disability?	81.9%	79.1%
Did you help develop this person’s service plan?	75.2%	49.8%
Does your service plan include things that are important to you?	87.8%	80.2%
Are staff generally respectful, courteous and knowledgeable?	88.5%	90.6%
<b>Choices and Control</b>		
Does the agency providing residential services to this person involve you in important decisions?	83.2%	78.2%
Does the agency providing day/employment services to this person involve you in important decisions?	76.7%	58.0%
Can you choose the support workers that work with your family member?	10.1%	8.3%
Can you have control and/or input over the hiring and management of your support workers?	5.1%	4.3%
Can you have control and/or input over the hiring and management of your support workers?	20.0%	21.9%
How much money is spent by the agency on behalf of your family member?	49.4%	27.7%
Can you get to decide how this money is spent?	35.8%	13.6%
<b>Access to Individual Services/Supports</b>		
If your person does not speak English, is there enough staff who can communicate with him/her?	79.2%	77.8%
Does your person have access to the special equipment or accommodations that s/he needs?	88.4%	89.0%
Do frequent changes in support staff a problem for your family?	31.4%	24.1%
Can you contact this person’s service coordinator whenever you want to?	82.6%	86.6%
When you ask the service coordinator for assistance, does s/he help you get what you need?	76.1%	83.5%
<b>Satisfaction with Individual Services/Supports</b>		
Do you feel that this person’s residential setting is a healthy and safe environment?	86.9%	89.8%
Do you feel that this person’s day/employment setting is a healthy and safe environment?	87.6%	90.8%
Have you been informed of your agency’s grievance process?	70.5%	53.5%
Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?	70.2%	71.4%
Do you feel that this person is happy?	83.8%	84.9%
Are you satisfied with the services and supports this person currently receives?	82.9%	85.7%

Brian Lensch, Program Administrator at 866-229-5553 for more information or for a copy of the report  
[www.hsri.org/cip/cipresults.html](http://www.hsri.org/cip/cipresults.html)

Dear Dr. Z,

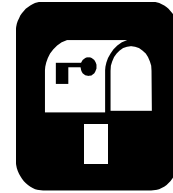
When I was at your office, I noticed some very interesting and wonderful pictures  
Someone said the artists are individuals with developmental disabilities. Is this true?

Inquisitive Mom

Dear Inquisitive,

Yes, we have been fortunate to enjoy some great art in Central Office. Displays have been courtesy of the Valley of the Sun, Herbert Yazzie, Alpine's Koyemsi Designs and Robert Tucker. Currently Valley of the Sun is displaying art for a second time. Marc Center will share in March and Hozhoni in April. The art is enjoyed and I extend appreciation to the artists for their talents and generosity.

Thanks,  
Ric Zaharia



## CHECK THESE WEB SITES

Taken from the IHD Community News Notes, February issue at [www.nau.edu/~ihd](http://www.nau.edu/~ihd)

[www.blackwell-science.com/products/journals/freepdf/ppe393.pdf](http://www.blackwell-science.com/products/journals/freepdf/ppe393.pdf) for an article, *Birth-Weight and Gestational Age Effects on Motor and Social Development*.

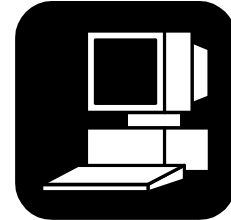
[www.nichd.nih.gov](http://www.nichd.nih.gov) for the report, *Educational Lag for Premature Infants Persists Into Adulthood*.

[www.cdfactioncouncil.org/action\\_agenda.htm](http://www.cdfactioncouncil.org/action_agenda.htm) for the *Children's Defense Fund's* wrap-up of congressional action on the Act to Leave No Child Behind.

[www.hsrnet.com/pubs/pub09.htm](http://www.hsrnet.com/pubs/pub09.htm) for the report, *Barriers to and Strategies for Improved Integration*.

[www.aypf.org](http://www.aypf.org) or [www.ctredpol.org](http://www.ctredpol.org) for the publication, *Twenty-Five years of Education Children with Disabilities: The Good News and the Work Ahead*.

[www.healthlaw.org](http://www.healthlaw.org) for the Time magazine story *Health: Where to Get Help in the Changing System*.



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Equal Opportunity Employer/Program Alternative formats by contacting 602-542-6825.

Arizona Department of Economic Security  
Quality Service, Organizational Pride,  
Client Self-Sufficiency